ERROR CORRECTION FORM

Sequence Number: CIBMTR Recipient ID: Initials:

Today's Date: Month Day Year 20__

Infusion Date: Month Day Year 20__

CIBMTR Center Number:

Wiskott-Aldrich Syndrome Pre-HSCT Data

Registry Use Only

Sequence Number:

Date Received:

CIBMTR Center Number:

CIBMTR Recipient ID:

Has this patient's data been previously reported to USIDNET?

1 ☐ yes → USIDNET ID:
2 ☐ no

Today's Date: Month Day Year 20__

Date of HSCT for which this form is being completed: 🕮 Month Day Year 20__

HSCT type: ☐ autologous ☐ allogeneic, unrelated ☐ allogeneic, related ☐ syngeneic (identical twin)

Product type: ☐ marrow ☐ PBSC ☐ cord blood ☐ other product, specify: ________

This form must be accompanied by Form 2000 – Recipient Baseline Data. All information in the box above, including the date, should be identical with the corresponding Form 2000. Information should come from an actual examination by the Transplant Center physician, or the physician who is following the recipient pre-HSCT, or abstraction of the recipient's medical records.

Questions followed by the symbol 🕮 indicate additional information necessary to complete the question is referenced in the forms instruction manual.

If this is a report of a second or subsequent transplant, check here ☐ and continue with question 79.

Disease Assessment at Diagnosis 🕮

Disease assessment at diagnosis includes disease characteristics observed within six weeks of the date of diagnosis.

1. What was the date of diagnosis of Wiskott-Aldrich Syndrome (WAS)? Month Day Year

2. Specify the WAS defining (diagnostic) criteria:

1 ☐ definitive → (definitive diagnosis defined as male patient with congenital thrombocytopenia (< 70,000 platelets/mm^3), small platelets, and at least one of the additional criteria at questions 3–6)

Specify all additional criteria for definitive WAS diagnosis:

3. 1 ☐ yes 2 ☐ no Mutation in WASp
4. 1 ☐ yes 2 ☐ no Absent WASp mRNA on northern blot analysis of lymphocytes
5. 1 ☐ yes 2 ☐ no Absent WASp protein in lymphocytes
6. 1 ☐ yes 2 ☐ no Maternal cousins, uncles or nephews with small platelets and thrombocytopenia

2 ☐ probable → (probable diagnosis defined as male patient with congenital thrombocytopenia (< 70,000 platelets/mm^3), small platelets, and at least one of the additional criteria at questions 7–10)

3 ☐ possible → (possible diagnosis defined as male patient with congenital thrombocytopenia (< 70,000 platelets/mm^3) and small platelets; or with splenectomy for thrombocytopenia and at least one of the additional criteria at questions 7–10)

Specify all additional criteria for probable / possible WAS diagnosis:

7. 1 ☐ yes 2 ☐ no Eczema
8. 1 ☐ yes 2 ☐ no Abnormal antibody response to polysaccharide antigens
9. 1 ☐ yes 2 ☐ no Autoimmune disease(s)
10. 1 ☐ yes 2 ☐ no Lymphoma / leukemia

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11. Was a WAS gene mutation identified?
   - 1 ☐ yes → 12. Specify gene mutation identified:
     - 1 ☐ nucleotides affected (e.g., 361C>T)
     - 2 ☐ predicted amino acid change (e.g., W14R)
   - 2 ☐ no

13. Was a WASp protein expressed?
   - 1 ☐ yes
   - 2 ☐ no
   - 3 ☐ unknown

Laboratory Studies at Diagnosis

Report findings prior to any first treatment of Wiskott-Aldrich syndrome.

14. Date CBC tested: Month Day Year 20__ (testing done within 6 weeks of diagnosis)

15. WBC: ______ . _ Specify units: 1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L ☐ not tested

16. Lymphocytes: __ % ☐ not tested

17. Eosinophils: __ % ☐ not tested

18. Polymorphonuclear leukocytes (PMN): __ % ☐ not tested

19. Hemoglobin: ____ . __ 1 ☐ g/dL 2 ☐ g/L 3 ☐ mmol/L ☐ not tested ☐ transfused RBC < 30 days from date of test

20. Platelets: _______ 1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L ☐ not tested ☐ transfused platelets < 7 days from date of test

21. Mean platelet volume: __ . _ fl ☐ not tested

Immunoglobulin Analysis

Specify the following quantitative immunoglobulins measured prior to any disease treatment:

	Value:	Specify units:		Date tested: Month Day Year	
22. IgG:	_____ . __	1 ☐ mg/dL 2 ☐ g/dL 3 ☐ g/L	23.	__ __ ____	☐ not tested
24. IgM:	_____ . __	1 ☐ mg/dL 2 ☐ g/dL 3 ☐ g/L	25.	__ __ ____	☐ not tested
26. IgA:	_____ . __	1 ☐ mg/dL 2 ☐ g/dL 3 ☐ g/L	27.	__ __ ____	☐ not tested
28. IgE:	___	IU/mL	29.	__ __ ____	☐ not tested

30. Did the recipient receive supplemental intravenous immunoglobulins (IVIG) prior to any first treatment of WAS?
   - 1 ☐ yes → 31. Was therapy ongoing within one month of immunoglobulin testing?
     - 1 ☐ yes
     - 2 ☐ no
   - 2 ☐ no
   - 3 ☐ unknown

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Lymphocyte Analysis

Specify the following lymphocyte analyses performed prior to any disease treatment:

32. Were lymphocyte analyses performed?
   1 ☐ yes →
   2 ☐ no

33. Date of most recent testing performed: Month / Day / Year

34. Absolute lymphocyte count: → ____ cells / µL (cells / mm^3)

	% of total lymphocytes:		Value:	Specify units:	
35. CD3 (T cells): →		– or –		1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L	☐ not tested
36. CD4 (T helper cells): →		– or –		1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L	☐ not tested
37. CD8 (cytotoxic T cells): →		– or –		1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L	☐ not tested
38. CD20 (B lymphocyte cells): →		– or –		1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L	☐ not tested
39. CD56 (natural killer (NK) cells): →		– or –		1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L	☐ not tested
40. CD4+ / CD45RA+ (naive T cells): →		– or –		1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L	☐ not tested
41. CD4+ / CD45RO+ (memory T cells): →		– or –		1 ☐ x 10^9/L (x 10^3/mm^3) 2 ☐ x 10^6/L	☐ not tested

Clinical Features Assessed between Diagnosis and the Start of the Preparative Regimen

Infections Identified between Diagnosis and the Start of the Preparative Regimen

Specify the presence of all clinically significant infections identified between diagnosis and the start of the preparative regimen. If any given infection was identified, use the Codes for Commonly Reported Organisms on the following page to report the organism present. Only report an organism once, even if it was identified at the same site in subsequent infections.

For questions 66–78, also report any fungal infections in the Form 2000 – Recipient Baseline Data beginning at question 163.

Copy this chart to report more than three different infections identified at any one site; check here ☐ if additional pages are attached.

Site of infection?		First organism	Second organism	Third organism	Specify other organism
42. 1 ☐ yes 2 ☐ no	Hepatitis →	43.	44.	45.	46. ______
48. 1 ☐ yes 2 ☐ no	Meningitis / encephalitis →	49.	50.	51.	52. ______

47. If hepatitis was present, was it a prominent feature of WAS?
   1 ☐ yes
   2 ☐ no

53. If meningitis / encephalitis was present, was it a prominent feature of WAS?
   1 ☐ yes
   2 ☐ no

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Initials: | |

Today's Date: __ __ (Month) __ __ (Day) 2 0 __ __ (Year)

Infusion Date: __ __ (Month) __ __ (Day) 2 0 __ __ (Year)

CIBMTR Center Number: | | | | | |

CIBMTR Center Number: | | | | | | CIBMTR Recipient ID: | | | | | | | | | | |

Site of infection?		First organism	Second organism	Third organism	Specify other organism
54. 1 ☐ yes 2 ☐ no	Pneumonia →	55. ☐☐☐	56. ☐☐☐	57. ☐☐☐	58. ______

59. If pneumonia was present, was it a prominent feature of WAS?
1 ☐ yes
2 ☐ no

60. 1 ☐ yes 2 ☐ no	Severe or protracted diarrhea →	61. ☐☐☐	62. ☐☐☐	63. ☐☐☐	64. ______

65. If diarrhea was present, was it a prominent feature of WAS?
1 ☐ yes
2 ☐ no

66. 1 ☐ yes 2 ☐ no	Systemic infection →	67. ☐☐☐	68. ☐☐☐	69. ☐☐☐	70. ______

71. If systemic infection was present, was it a prominent feature of WAS?
1 ☐ yes
2 ☐ no

72. 1 ☐ yes 2 ☐ no	Other infection →	73. ☐☐☐	74. ☐☐☐	75. ☐☐☐	76. ______

77. Specify other infection site: ______________________

78. If other infection was present, was it a prominent feature of WAS?
1 ☐ yes
2 ☐ no

Codes for Commonly Reported Organisms

Bacterial Infections

121 Acinetobacter
122 Actinomyces
123 Bacillus
124 Bacteroides (gracillis, uniformis, vulgaris, other species)
125 Bordetella pertussis (whooping cough)
126 Borrelia (Lyme disease)
127 Branhamella or Moraxella catarrhalis (other species)
128 Campylobacter (all species)
129 Capnocytophaga
171 Chlamydia pneumoniae
172 Other chlamydia, specify
113 Chlamydia, NOS
130 Citrobacter (freundii, other species)
131 Clostridium (all species except difficile)
132 Clostridium difficile
173 Corynebacterium jeikeium
133 Corynebacterium (all non-diptheria species)
101 Coxiella
134 Enterobacter
177 Enterococcus, vancomycin resistant (VRE)
135 Enterococcus (all species)
136 Escherichia (also E. coli)
137 Flavimonas oryzihabitans
138 Flavobacterium
139 Fusobacterium
144 Haemophilus (all species, including influenzae)
145 Helicobacter pylori
146 Klebsiella
147 Lactobacillus (bulgaricus, acidophilus, other species)
102 Legionella
103 Leptospira
148 Leptotrichia buccalis
149 Leuconostoc (all species)
104 Listeria
150 Methylobacterium
151 Micrococcus, NOS
112 Mycobacterium avium– intracellulare (MAC, MAI)
174 Mycobacterium species (cheloneae, fortuitum, haemophilum, kansasii, mucogenicum
110 Mycobacterium tuberculosis (tuberculosis, Koch bacillus)
175 Other mycobacterium, specify
176 Mycobacterium, NOS
105 Mycoplasma
152 Neisseria (gonorrhoea, meningitidis, other species)
106 Nocardia
153 Pasteurella multocida
154 Propionibacterium (acnes, avidum, granulosum, other species)
155 Proteus
156 Pseudomonas (all species except cepacia & maltophilia)
157 Pseudomonas or Burkholderia cepacia
158 Pseudomonas or Stenotrophomonas or Xanthomonas maltophilia
159 Rhodococcus
107 Rickettsia
160 Salmonella (all species)
161 Serratia marcescens
162 Shigella
163 Staphylococcus, coagulase negative (not aureus)
164 Staphylococcus aureus
165 Staphylococcus, NOS
166 Stomatococcus mucilaginosis
167 Streptococcus (all species except Enterococcus)
178 Streptococcus pneumoniae
168 Treponema (syphilis)
169 Vibrio (all species)
197 Multiple bacteria at a single site, specify bacterial codes
198 Other bacteria, specify ‡
501 Suspected atypical bacterial infection
502 Suspected bacterial infection

Fungal Infections

200 Candida, NOS
201 Candida albicans
206 Candida guillermondi
202 Candida krusei
207 Candida lusitaniae
203 Candida parapsilosis
204 Candida tropicalis
205 Candida (Torulopsis) glabrata
209 Other Candida, specify ‡
210 Aspergillus, NOS §
211 Aspergillus flavus §
212 Aspergillus fumigatus §
213 Aspergillus niger §
219 Other Aspergillus, specify ‡ §
220 Cryptococcus species
230 Fusarium species §
261 Histoplasmosis
240 Zygomycetes, NOS §
241 Mucormycosis §
242 Rhizopus §
250 Yeast, NOS
259 Other fungus, specify ‡
260 Pneumocystis (PCP / PJP)
503 Suspected fungal infection

Viral Infections

301 Herpes simplex (HSV1, HSV2)
302 Varicella (herpes zoster, chicken pox)
303 Cytomegalovirus (CMV)
304 Adenovirus
305 Enterovirus (coxsackie, echo, polio)
306 Hepatitis A (HAV)
307 Hepatitis B (HBV, Australian antigen) †
308 Hepatitis C (HCV) †
309 HIV-1 (HTLV-III) ¤
310 Influenza, NOS
323 Influenza A
324 Influenza B
311 Measles (rubeola)
312 Mumps
313 Progressive multifocal leukoencephalopathy (PML)
314 Respiratory syncytial virus (RSV)
315 Rubella (German measles)
316 Parainfluenza
317 Human herpesvirus-6 (HHV-6)
318 Epstein-Barr virus (EBV)
319 Polyoma virus (BK virus, JC virus)
320 Rotavirus
321 Rhinovirus
322 Human papilloma virus (HPV)
329 Other virus, specify ‡
504 Suspected viral infection

Parasitic Infections

402 Toxoplasma
403 Giardia
404 Cryptosporidium
409 Other parasite, specify ‡
505 Suspected parasite infection

Other Infections

509 No organism identified

‡ The codes for "other organism, specify" (codes 198, 209, 219, 259, 329 and 409) should rarely be needed; check with your microbiology lab or HSCT physician before using them.

§ For fungal infections marked with a section symbol (codes 210, 211, 212, 213, 219, 230, 240, 241, and 242), also complete a Fungal Infection (FNG) form.

† For hepatitis infections marked with a dagger symbol (codes 307 and 308), also complete a Hepatitis (HEP) form.

¤ For HIV infections marked with a currency symbol (code 309), also complete an HIV Infection (HIV) form.

* Do not report fever in the absence of infection. Report the most specific site of infection.

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CIBMTR Center Number: ☐☐☐☐☐ CIBMTR Recipient ID: ☐☐☐☐☐☐☐☐☐☐

Clinical Status Between Diagnosis and the Preparative Regimen

79. Did the recipient undergo a splenectomy (between diagnosis and prior to the preparative regimen)?
   - 1 ☐ yes →
   - 2 ☐ no
   - 3 ☐ unknown

   80. Specify the date the splenectomy was performed: ☐☐ (Month) ☐☐ (Day) 2 0 ☐☐ (Year)

   81. Platelets (after splenectomy): ☐☐☐☐☐☐☐
   - 1 ☐ x 10^9/L (x 10^3/mm^3)
   - 2 ☐ x 10^6/L
   - ☐ not tested
   - ☐ transfused platelets < 7 days from date of test

82. Were thrombocytopenia (< 100 x 10^9/L) and small platelets present without any other symptoms, clinical findings, or laboratory abnormalities attributable to WAS (between diagnosis and prior to the preparative regimen)?
   - 1 ☐ yes → **Specify thrombocytopenia in the Form 2000 — Recipient Baseline Data at questions 117–118**
   - 2 ☐ no
   - 3 ☐ unknown

83. Was eczema present as a clinical feature (between diagnosis and prior to the preparative regimen)?
   - 1 ☐ yes →
   - 2 ☐ no
   - 3 ☐ unknown

   84. Specify severity of eczema:
   - 1 ☐ mild, transient
   - 2 ☐ persistent but manageable
   - 3 ☐ difficult to control

85. Was a coexisting malignancy present (between diagnosis and prior to the preparative regimen)?
   - 1 ☐ yes →
   - 2 ☐ no
   - 3 ☐ unknown

   86. Specify malignancy: ______________________

   Report malignancy in the Form 2000 — Recipient Baseline Data at questions 23–60

87. Did the recipient experience any of the following types of bleeding episodes (between diagnosis and prior to the preparative regimen)?
   - 1 ☐ yes →
   - 2 ☐ no

   Specify types of bleeding:

	Bleeding episode(s) present?			If present, is the feature prominent?	
88.	1 ☐ yes 2 ☐ no	Epistaxis →	89.	1 ☐ yes 2 ☐ no	
90.	1 ☐ yes 2 ☐ no	Upper GI hemorrhage →	91.	1 ☐ yes 2 ☐ no →	**Report GI hemorrhage in the Form 2000 — Recipient Baseline Data at question 63**
92.	1 ☐ yes 2 ☐ no	Lower GI hemorrhage / rectal bleeding →	93.	1 ☐ yes 2 ☐ no →	**Report GU hemorrhage in the Form 2000 — Recipient Baseline Data at question 64**
94.	1 ☐ yes 2 ☐ no	Hemarthrosis →	95.	1 ☐ yes 2 ☐ no	
96.	1 ☐ yes 2 ☐ no	Hematuria →	97.	1 ☐ yes 2 ☐ no	
98.	1 ☐ yes 2 ☐ no	Intracranial hemorrhage →	99.	1 ☐ yes 2 ☐ no →	**Report CNS hemorrhage in the Form 2000 — Recipient Baseline Data at question 65**
100.	1 ☐ yes 2 ☐ no	Oral →	101.	1 ☐ yes 2 ☐ no	
102.	1 ☐ yes 2 ☐ no	Subcutaneous bleeding →	103.	1 ☐ yes 2 ☐ no	
104.	1 ☐ yes 2 ☐ no	Subdural hematoma →	105.	1 ☐ yes 2 ☐ no	
106.	1 ☐ yes 2 ☐ no	Other bleeding →	107.	1 ☐ yes 2 ☐ no	

   108. Specify other bleeding: ______________________

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CIBMTR Center Number: ☐☐☐☐☐ CIBMTR Recipient ID: ☐☐☐☐☐☐☐☐☐☐

109. Did the recipient experience any of the following autoimmune / inflammatory disorders (between diagnosis and prior to the preparative regimen?)
1 ☐ yes →
2 ☐ no

Specify autoimmune / inflammatory disorders:

Feature present?		If present, is the feature prominent?
110. 1 ☐ yes 2 ☐ no	Arthralgia →	111. 1 ☐ yes 2 ☐ no
112. 1 ☐ yes 2 ☐ no	Arthritis, chronic →	113. 1 ☐ yes 2 ☐ no
114. 1 ☐ yes 2 ☐ no	Autoimmune hemolytic anemia →	115. 1 ☐ yes 2 ☐ no
116. 1 ☐ yes 2 ☐ no	Idiopathic thrombocytopenic purpura (ITP) →	117. 1 ☐ yes 2 ☐ no
118. 1 ☐ yes 2 ☐ no	Inflammatory bowel disease →	119. 1 ☐ yes 2 ☐ no
120. 1 ☐ yes 2 ☐ no	Juvenile rheumatoid arthritis →	121. 1 ☐ yes 2 ☐ no
122. 1 ☐ yes 2 ☐ no	Nephritis →	123. 1 ☐ yes 2 ☐ no
124. 1 ☐ yes 2 ☐ no	Neutropenia →	125. 1 ☐ yes 2 ☐ no
126. 1 ☐ yes 2 ☐ no	Sclerosing cholangitis →	127. 1 ☐ yes 2 ☐ no
128. 1 ☐ yes 2 ☐ no	Vasculitis, cerebral →	129. 1 ☐ yes 2 ☐ no
130. 1 ☐ yes 2 ☐ no	Vasculitis, coronary →	131. 1 ☐ yes 2 ☐ no
132. 1 ☐ yes 2 ☐ no	Vasculitis, renal →	133. 1 ☐ yes 2 ☐ no
134. 1 ☐ yes 2 ☐ no	Vasculitis, skin →	135. 1 ☐ yes 2 ☐ no
136. 1 ☐ yes 2 ☐ no	Vasculitis, other →	137. 1 ☐ yes 2 ☐ no
	138. Specify other vasculitis: ______	
139. 1 ☐ yes 2 ☐ no	Other disorder →	140. 1 ☐ yes 2 ☐ no
	141. Specify other disorder: ______	

142. Were any biologic specimens collected for this recipient (between the date of diagnosis and the preparative regimen)?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

Specify if specimen(s) collected and available for future research:

143. 1 ☐ yes 2 ☐ no DNA
144. 1 ☐ yes 2 ☐ no Epstein-Barr virus (EBV)-transformed B-cell line
145. 1 ☐ yes 2 ☐ no Fibroblast cell line
146. 1 ☐ yes 2 ☐ no Herpes virus saimiri-transformed T-cell line
147. 1 ☐ yes 2 ☐ no Other T-cell line
148. 1 ☐ yes 2 ☐ no Pathological specimen → 149. Specify pathological specimen(s): ______
150. 1 ☐ yes 2 ☐ no Peripheral blood mononuclear cells (PBMC), frozen
151. 1 ☐ yes 2 ☐ no RNA → 152. Specify RNA source: ______
153. 1 ☐ yes 2 ☐ no Serum (pre-IVIG)
154. 1 ☐ yes 2 ☐ no Other specimen → 155. Specify other specimen(s): ______

156. Signed: ______
Person completing form

Please print name: ______

Phone: (______) ______

Fax: (______) ______

E-mail address: ______

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